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Ethical Issues in Diagnosing and Treating Alzheimer Disease

ABSTRACT

Many unique ethical issues arise when diagnosing and treating Alzheimer disease (AD). This article discusses several core ethical dilemmas that arise for psychiatrists during different stages of AD, focusing particularly on areas of consensus and controversy. Issues addressed include screening, genetic testing, and discussions of advance directives during early stages; telling soft and even outright lies during middle and late stages; and withholding life-preserving interventions during the last stage of AD when death is imminent. While there is overwhelming ethical consensus that psychiatrists should be fully honest and respect patient autonomy as much as possible during the early stages of disease, there is more controversy regarding the extent to which psychiatrists should do this during the later stages of disease. Possible, optimal approaches to resolving these ethical issues are presented.



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INTRODUCTION

Alzheimer disease (AD) is extremely common, and its incidence increases as persons get older.¹ At this time, there are approximately 4.5 million patients in the country with this illness, and by 2050 it is expected that this number will triple.² The incidence of this illness doubles about every five years after the age of 65. Thus, almost 50 percent of persons may be affected by age 85.³ It is, therefore, highly likely that psychiatrists will encounter this illness at some point in their patients or their patients' families.

Many aspects of making this diagnosis and managing this disease raise difficult ethical questions.

Consequently, psychiatrists working with AD patients or their family members should consider contemporary views when addressing these questions so that they can provide these patients optimal care. The terms *family members*, *caregivers*, and *loved ones* are used interchangeably throughout the article and represent anyone outside of the medical profession who cares for an AD patient. This paper will identify several core ethical problems posed when caring for AD patients and will present current thinking and controversies regarding them. The discussion will address these problems in the same order in which they tend to arise during the course of the AD.^{4,5} Problems that occur early on in AD primarily involve the question of the extent to which to respect patient autonomy. These problems include when psychiatrists should refer patients for more definitive diagnostic testing, what psychiatrists should do when AD patients request genetic screening, and the extent to which psychiatrists should discuss with AD patients the worst outcomes they could

experience when discussing advance directives.

Problems that occur in the middle and later stages of AD primarily involve conflicts between the values of respecting patient autonomy maximally and paternalistically trying to protect them. These problems include whether the AD patient's caregivers should try to influence the patient in ways they don't disclose to get him or her to do

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what they want, whether they should withhold information because it may be highly upsetting to the patient, and, especially during the later stages of AD, whether caregivers should outright lie to the patient to avoid causing psychological stress.

As AD patients near death, questions may arise regarding the extent to which all efforts should be undertaken to try to keep these patients alive. As the AD patient's condition deteriorates, his or her existence may be fraught with exceptional stress. When this occurs, while his or her life still holds value, some feel that it is more humane to let the patient die. To best illustrate the ethical issues these situations typically involve, this article will discuss specific problems associated with eating as a paradigm for other problems encountered when treating people with late-stage AD. The problems associated with eating that will be addressed include when patients can no longer eat enough food by mouth to sustain his or her weight and when the patient loses the ability to eat altogether.^{6,7}

While there is now an overwhelming consensus that psychiatrists should respect the autonomy of AD patients as fully and for as long as possible, interventions that were at one time ethically optimal become increasingly controversial as the disease in these patients worsens. As patients with AD lose their capacity to understand and/or to control their behavior, it may be necessary for psychiatrists and caregivers to give greater moral weight to values other than respecting patient autonomy.

Psychiatrists may, at this time, have greater justification in using their own ethical judgment and discretion. It may be optimal for them to try to tailor their interventions, as best they can, to the individual needs of the AD patients and their family members. If psychiatrists can't do this, especially in the later stages of the disease, their clinical interventions may be suboptimal.

ETHICAL PROBLEMS THAT OCCUR IN THE EARLY STAGES OF AD

Seeking a more definitive diagnosis. The first issue a psychiatrist is likely to confront when treating a patient with AD is when to initiate more elaborate, formal testing. The diagnosis of AD can be made with certainty only after death, though this may change in the future.⁸ Neuroimaging techniques, for example, now allow visualization of amyloid plaques, the pathological hallmarks of AD. Plaque accumulation takes place, however, only late in the course of this disease. Developments in nanobiotechnology may be more promising.^{3,9}

Currently, once AD is suspected, initial efforts should be made to rule out other conditions with similar signs and symptoms. This is especially important since many of

these other conditions may be reversible.⁹ The more elaborate testing is necessary to decrease the proportion of false positive and false negative results.⁹

False positive and false negative results can be exceedingly harmful. False positive results can cause patients to experience life-shattering fear that is unwarranted. False negatives results can, on the other hand, lead to patients not seeking care as early as possible in the course of the disease. While proper care early on in AD will not change the ultimate course of this disease, there are pharmacological and psychological interventions available that can slow the process of AD, especially when used early in the course of the disease.¹⁰⁻¹²

When a patient first reports memory problems, the psychiatrist should be predisposed to initiating some form of screening for AD. Some psychiatrists believe AD screening should be performed annually for any patient over 65 and for younger patients with a positive family history for AD.²

Several initial screening measures are available for this purpose. These range from the psychiatrist performing a mental status exam to asking patients to draw a clock to administering several brief tests that have been specifically constructed for this purpose.^{2,13-15} Patients can also test themselves with measures that are available commercially.^{2,10,16}

The above described screening measures often are more suggestive than conclusive, so when positive results occur, the psychiatrist should refer the patient for more formal diagnostic testing, which should include a neurological exam and laboratory blood tests. If the results of the more formal screening are negative, the psychiatrist should reassure the patient that the diagnosis of AD, at this time at least, is unlikely.

If negative results occur from the initial screening process with the psychiatrist, some patients may still feel exceptionally fearful. If so, it is best to then refer them for the formal testing in order to reduce their fears. While this is open to controversy, referring these patients may, in addition, strengthen the patient/psychiatrist relationship. This, in turn, may increase the likelihood that such patients will return for testing later if their memory problems worsen.

The core ethical question posed when a patient reports memory problems is the degree to which the psychiatrist should inform the patient of the risk of AD, urge him or her to be screened, and, if indicated, recommend further testing. This core question is, however, the least difficult of those that I address in this article. The answer, as I indicated already, is unequivocally yes—patients should be informed of the risk of AD, patients should be screened, and if indicated patients should undergo formal testing for AD.¹⁷

Not long ago, medicine had less to offer patients with AD. It was feared that if a psychiatrist informed a

the early stages of the disease with a high level education and with preserved insight who perceive that they are not responding to pharmacological treatment may be at increased suicide risk, even when depression and other classic risk factors are absent.”¹⁸

Notwithstanding this concern, two arguments strongly favor psychiatrists pursuing AD testing. First, as stated previously, patients may gain more from the early use of drugs and early psychological interventions. Second, it was feared primarily on the basis of logic and not research that in addition to the rare patient who might take his or her own life, most patients, upon learning that they have this disease, would become exceptionally depressed. It is now known, however, that in response to learning that they have AD, most patients do not become depressed.¹⁹⁻²¹

The finding that most patients do not respond to the diagnosis of AD by becoming depressed has significant implications also for the next two ethical problems I discuss: genetic testing and discussing advance directives with AD patients. Psychiatrists can refer AD patients for genetic testing and discuss

advance directives with them without the outcome of depression being a major concern.

The one major ethical exception and possible contraindication to psychiatrists

informing patients of the possibility of AD and urging them

to pursue proper testing is when patients state initially that they don't want to know this information and continue to make this request.²² Then, psychiatrists should comply with this request to respect patient autonomy, despite the fact that patients may indeed be harmed as a result of not acquiring this information. Psychiatrists should in

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patient of the possibility of AD, he or she might respond by taking his or her own life. In balancing these two considerations, some psychiatrists felt that avoiding the risk of suicide was more important than respecting patient autonomy. Though this response is extremely rare, the risk of suicide still exists today and should be considered. “Patients at

these instances inform the patients of the risks of not being screened, without pressuring them to change their minds. This may, in the long run, be more beneficial to these patients, as this approach may enhance the likelihood that the patients will return at a later time.

A final ethical question that may arise for psychiatrists regarding the pursuit of initial and formal testing for AD is whether psychiatrists should openly offer all of their patients the option of not undergoing testing as opposed to leaving this option available only to patients who make this request on their own. While this approach is rarely considered, psychiatrists taking this initiative in all such cases would further the moral principle of equity. It would increase the likelihood that less assertive patients who do not want to be screened would choose the option of no screening. All patients, however, may feel more respected by being given the choice of testing or no testing. Psychiatrists taking this initiative may, paradoxically, not only respect patient autonomy to a greater extent, but also ultimately enhance patient care.

Responding to patients who request genetic testing. Even if beneficial treatments don't exist for a disease, psychiatrists should give patients who want it access to information about their conditions so long as the findings have meaningful prognostic implications. The paradigmatic example here is Huntington's disease. Even though there is also no current treatment for this disease, the ethical consensus currently is that psychiatrists should give these patients access to genetic testing if they want it, because this and this alone respects patient autonomy. This information can benefit them substantially by enabling them to make better plans for their futures.

Genetic testing for AD has, however, wholly different implications than genetic testing for Huntington's disease.^{23,24} The Alzheimer genotype is only "a marker for susceptibility, not the disease itself."²⁵ Should this make a difference?

In general, at least until recently,

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it was the overwhelming consensus, both clinically and in research contexts, that psychiatrists and other physicians should not comply with requests for genetic information regarding AD, at least when patients were asymptomatic, because, as one author states, "the data are not very useful."²⁵ A possible exception regarding testing for the APOE genotype is when this is "as an adjunctive diagnostic test for those patients already presenting with dementia."²⁵

Likewise, it has been common practice during early genetic research that the researchers would inform participants from the outset that the participants would not be allowed access to their test results. The rationale for this has been that the clinical relevance of these results is insufficiently established to be meaningful.

This approach is paternalistic. It presupposes the overriding ethical importance of protecting patients from information that could be harmful. Yet, many patients want to be tested for the APOE genotype, especially when they have a positive family history for AD. Many also feel that they have benefited from being

tested for the APOE genotype even when the result is positive.

In one recent study, for example, adult children of parents who had AD were offered the opportunity to be tested for the APOE genotype. If present, this would, of course, enhance the likelihood that they would have this disease. A quarter of this group "not only wanted to know but volunteered to participate in the trial and have blood drawn." Further, of those who tested positive, 95 percent indicated that they would want to go through this risk assessment again.²⁵

It is relevant when considering this clinical question that leading ethical authorities on research ethics recently recommended that the traditional, paternalistic practice of withholding results of genetic research ethically may be wrong. They state, "The current disclosure policy should be reconsidered in light of data that suggest that the prevalence of distress caused to participants by disclosure is low."²⁶

One rationale behind this change in both clinical and research ethical practices is that patients and research participants may find even highly preliminary results meaningful long before they meet standards of scientific significance. Psychiatrists could, in such cases, explain to patients what even the most preliminary results mean or don't mean. Some have argued that patients not trained in medicine can't understand what it means to have results that aren't scientifically meaningful, and, thus, giving patients this information unduly subjects them to harm. This claim that patients can't understand enough to make choices for themselves now is widely rejected.

Accordingly, it may be that participants in research should have greater access to preliminary genetic

results, and likewise that psychiatrists might be ethically justified in giving selected patients greater access to APOE genotype testing, even if the patients are asymptomatic. By providing this access, it may enhance the patient/psychiatrist relationship, which in turn may enhance the likelihood that these patients will seek treatment at a later time.

A final concern regarding genetic testing is how insurance companies will respond.²⁷ Here, by and large, there are unclear answers. Consequently, the present ethical standard for psychiatrists is to inform patients before they decide to pursue genetic testing that insurance coverage could be a problem. Patients wanting this testing, but not knowing how insurance companies will respond, are in a bind. Yet respecting patient autonomy by giving patients this choice as opposed to making this decision for them by refusing to give them access to genetic testing may in most instances be the preferable option.

Advance directives. During the middle and late stages of AD, patients may lose the capacity to determine and express what they want. To maximally respect patient autonomy when they become incompetent, it is now common practice to ask these patients during the earlier stages of AD what they want done and/or who will make decisions for them when they are no longer able make these decisions themselves. The current view is that psychiatrists should ask all patients with AD whether they want to express these preferences in advance directives. "First of all, you should include the person with AD in decisions regarding his or her welfare whenever possible."²⁸⁻³⁰ Psychiatrists may be reluctant to pursue these discussions, however, for several reasons.³¹ They may fear,

as already discussed, that if they discuss worst possible future outcomes with their patients that these patients may become unduly depressed. Even if this fear is unwarranted, other fears are not. The painful images patients envision while considering their advance directives may, for example, cause them harm even if they do not become depressed. One patient, for instance, was using positive imagery to try to fight his cancer. He then envisioned several dismal, possible outcomes when considering his advance directives. After he had done this, he could no longer create this same positive imagery to try to fight his cancer with it as he had.

Negative outcomes that patients with AD may envision when considering advance directives may include no longer being able to eat, being on a respirator, and needing to be in restraints.^{7,32} Another undesirable outcome is becoming so explosively angry that he or she attacks those he or she has known and loved for decades but is no longer able to recognize.^{23,33,34} Should psychiatrists ask these patients to consider all of these outcomes?

At all stages of their illness, most AD patients want to remain as fully involved in determining their futures as possible. They also want to remain as fully involved as possible with their families. Discussing their advance directives with their families present allows AD patients to help determine their futures and to emotionally bond with family members. This opportunity is also

important to family members because it allows them to feel that they know what their loved one with AD wants and to remain more emotionally supportive.

Family members of AD patients will find that their caregiving duties will become increasingly difficult as the disease course worsens. Family members must accept the loss of the person their loved one once was, while at the same time not becoming too emotionally distant from the person their loved one has become.³⁵

Family members often struggle trying to decide what their loved one, now incompetent, would want. If the person with AD hasn't discussed advance directives beforehand with his or her family, his or her family members will find it difficult to decide whether or not to initiate life-preserving care. If, however, the AD patient has expressed his or her preferences with the family members, it makes these decisions, when the time comes, much less difficult and stressful for the family members.

When AD patients are competent, psychiatrists should be paternalistic in this case and should encourage AD patients not only to discuss their

advance directives but to discuss them with their family members present.^{36,37}

During these discussions, psychiatrists again should be paternalistic and intervene whenever the AD patients or their family members show signs that they are exceptionally distressed. The psychiatrist then should ask the person who is distressed what he or she is thinking or feeling. If psychiatrists do this, the risks of discussing even the worst possible outcomes to the AD patients are likely to be much less. This is because sharing these painful feelings and associations may help reduce later intensity of these feelings, much as it will in most kinds

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of psychotherapy.

How far should these discussions go? One approach is to directly ask the AD patient this same question. A presupposition of psychiatrists asking AD patients about their advance directives is that the patients, when competent, will be able to decide the outcomes of “the persons” they will become as the disease progresses. Something to consider is that while AD patients may wholly lose the capacity to recognize others, they may also, at same time, appear to enjoy their lives.³⁸ These patients, when competent, may believe that they wouldn’t want to remain alive in this advanced disease state. Yet, some hold that at this later time, when these patients lack memory and seem “happy,” they are different persons altogether. They argue on this basis that when persons with early AD determine their advance directives, they shouldn’t be allowed to deny life-preserving measures to the persons they may later become.

Many experts vigorously oppose this argument. Post states, for example, “Such critics present a [sic] idealized image of the person with moderate dementia who is enjoying the moment. What they neglect is the brutal reality that this disease is going to enter an advanced and terminal stage that might be grossly protracted in the absence of an indication of wishes...[Also they] have badly understated the importance of assuring intact persons that...their wishes against the protraction of morbidity in the advance stage of AD will be honored.”³⁶

An “intermediate position” between these two sides is possible. It may be suggested that if an AD patient’s advance directives indicate that life-preserving measures should be withheld, the patient can indicate

that they only be withheld if and when it appears the patient has lost his or her apparent happiness and begins to suffer. Presently, this seems especially plausible since better measures are available for determining when incompetent patients are experiencing pain.³⁹ It is possible, in any case, for psychiatrists to ask AD patients while they are competent if this is an arrangement they would like to consider. Psychiatrists should be aware that even if these patients already have expressed their advance directives for medical illnesses unrelated to AD, their preferences may differ profoundly regarding the outcomes of AD.⁴⁰

Finally, when should the advance directives discussions stop with the AD patient? If an AD patient says he or she wants to discuss advance directives but becomes extremely distressed when discussing them, the psychiatrist can point out the emotional responses the patient is having and then ask him or her whether, in light of these, it makes sense to continue. This protects patient autonomy. Yet, the time may come when a patient becomes so distressed when discussing these matters that the psychiatrist and family members may feel they have

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no choice but to discuss these matters without the patient being present. If this occurs, it will involve implicit deception since the psychiatrist and family won’t be telling the patient all that is said. If they did, there would be no need to meet separately.

Should psychiatrists and family members violate the integrity of their relationships with these patients in this way? This kind of question is the focus of the problems in the next section.

ETHICAL ISSUES IN THE MIDDLE AND LATER STAGES

Over time, AD patients may lose their capacity to make decisions independently. At this time, family members may discover ways in which they can respond to their loved ones with AD that benefit the patient, but which aren’t fully open and honest.

In the discussions that follow, the ethical dilemmas that occur regarding AD patients are greater for the family members than for their physicians. The ethical questions discussed previously in the first section of this article, which involved screening and discussing advance directives, arise between the patients and their psychiatrists. The ethical considerations I shall discuss from this point on have a different purpose. As opposed to being relevant to psychiatrists and the difficult decisions they may have to make, the following discussion is intended to assist psychiatrists in best helping the family members of AD patients with difficult decisions family members have to make.

“Soft” lying. People who work with AD patients may recognize that if they give AD patients several choices, AD patients generally choose the last choice they were given. This tendency is called the “last-word connection.”²⁸

Here’s how this approach works: “The caregiver asks, ‘Would you like to wear this green shirt today or the one that’s blue?’ Nine times out of 10, the patient says, ‘Blue’ —simply because it was the last word he remembered hearing.”²⁸

One important benefit from caregivers doing this is that this

allows AD patients to retain a greater sense of self esteem. Doing this also satisfies the general recommendation by experts on how to most help these patients: "Guide the patient or take over as inconspicuously as possible to allow him to maintain a sense of control for as long as possible."²⁸ The patient's sense of control in this instance is, of course, illusory. This approach of using the last-word connection also meets the spirit of a similar, equally valuable rule-of-thumb: "If you can't give a truthful answer that is believable or acceptable or not hurtful at the cognitive level, then tell an emotional truth."³⁰

This approach is ethically problematic, of course, because it violates and departs from the continuing integrity families have maintained with these patients throughout the earlier stages of the patients' disease. These patients may remain totally emotionally aware, even when they are greatly cognitively impaired. Thus, these patients may sense this unprecedented loss of integrity and then feel angry or emotionally abandoned.

A second question involving "soft lying" is posed when these patients face a future event about which they feel afraid. This may be, for example, seeing a doctor or going to a nursing home.

As with young children who are frightened by an upcoming event, family members may not tell an AD patient about a feared event too far in advance, because if they do, the patient may experience painful apprehension for a much longer time. The price the family members may have to pay by not telling the AD patient earlier about the feared event may be a lost sense of trust or a fear by the AD patient that his or her caregiver(s) are no longer treating them as equals. These

patients may then feel isolated and enraged.

"Why didn't you tell me before this?" they might then exclaim. Family members who withheld the information are then faced with the same dilemma albeit in another guise. Should they try then to "minimize damages" by lying again?

Most authorities favor...giving [AD] patients emotional peace rather than cognitive truth, but not all experts agree.

They might say, for example, "Oh, I'm sorry, I forgot," though they had not.

One expert advises being honest. "Say something like, 'Sometimes I just don't know what to say.' Be rueful. You could add, 'Did that ever happen to you?'"³⁰

"Hard" lying. As the AD patient's disease worsens, the patient may forget more and more. He may forget, for instance, where he put something. Recognizing that he may have forgotten, however, may be too psychologically painful for him to accept. Consequently, he may deny it. Then, rather than accept that when he can't find something it is his "fault," he may conclude that a family member has stolen it. What should family members do then? Family members may face the same kind of limited choice, but in this case, their dilemma may be harder. If they confront him and tell him honestly what went wrong, the AD patient may not believe them. Worse, the patient may then incorporate what the family member said into a persecutory delusion.

The caregiver's other choice is to outright lie. She could say to the AD patient, "I'm sorry, I borrowed your scarf [or socks - or shirt] but I forgot to tell you."³⁰ The patient may still feel angry, but may not feel the fear

he may have felt in response to his loved one confronting him with the fact that his memory is as bad as it is.

Memory difficulties may manifest themselves in other ways. Each may pose analogous ethical dilemmas. The AD patient may, for example, repeat the same question over and over again. In this situation, experts say that loved ones should not say, "You just told me that." Rather, they should say, "That's interesting. I didn't know that," even though this is a lie.³⁰

"Every time they ask the question," the experts point out, "it is a new question to them. You must act as if it is a new question to you."³⁰

Other experts suggest this advice should apply even when, after years together, these patients forget who family members are. If the patient asks, "Do I know you?" experts suggest that the family member says "No, we haven't met before, but it's really nice to meet you."²⁸

Perhaps the "acid test" of this ethical dilemma is what loved ones should do when the widow or widower AD patient frequently asks, "Where is my husband (or wife)?" Family members may find that if they answer honestly, the AD patient responds, again and again, with overwhelming grief. Yet, if the loved ones say, "Oh he went out to the store," the patient may not feel grief but repeatedly respond with equanimity, saying merely, "Okay."

In situations like this, most authorities favor responding as I have indicated above by giving these patients emotional peace rather than cognitive truth, but not all experts agree. Some experts believe that even in the most extreme situations, caregivers should never lie to AD patients. If these patients don't remember that their spouses have died, these experts recommend saying, "I have such special memories of Dad. It's hard to imagine

that he's been gone now for 10 years. Tell me about Dad." They say that being untruthful about a person's death "oversteps the bounds of caregiver integrity and could backfire in obvious ways."⁴¹

In situations like this, when family members of AD patients ask for advice, what should psychiatrists say? What to do in these situations is open to debate. What is ethically most right or wrong? The psychiatrist is probably most justified in using his or her best judgment and discretion and giving advice based on the individual needs of each AD patient and his or her family members.

Some caregivers might feel a great deal of stress from causing AD patients additional emotional pain. If lying to the AD patient enables the family members to decrease patient pain, this ultimately will benefit the family members and the patient. This may also decrease the need some family members may feel to distance themselves from the patient.

Other caregivers may feel a greater deal of stress from violating their integrity with the AD patient by lying. They may respond better, which in turn benefits the patient more, by never lying.

In many instances, psychiatrists can help their patients most by helping the patients' caregivers, because the caregivers are with these patients for most of the day. Thus, if psychiatrists are able to help the caregivers over the shorter run by meeting the caregivers' emotional needs, this in the long run should help the patients.⁴²

Recent data based on autopsy studies provide yet another reason why psychiatrists should encourage caregivers to do whatever they must to enhance and maintain their positive social interactions with these patients. These data indicate that the more AD patients remain socially connected, the less

cognitively impaired they are likely to become. This may be because the social interactions trigger greater activity in alternative brain pathways. These other neural networks may fill in and function as compensatory, substitute neural networks where the patients have deficits.⁴³

ETHICAL DILEMMAS IN THE LAST STAGES OF AD

Ethical dilemmas continue to arise during the last stages of AD disease as the patient's medical

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condition worsens. Chief among these concerns is when and whether to continue life preserving treatment. This dilemma arises in many guises, but the example I discuss is losing the capacity to adequately eat, which will represent other physical conditions a patient in the late stages of AD may experience, such as whether to give antibiotics for pneumonia or begin kidney dialysis after a patient's kidney has failed.

The first issue that may arise regarding eating is when the AD patient can no longer eat enough by mouth to maintain his or her weight.⁶ The choices include whether to begin nasogastric tube feedings, perform a gastrostomy and surgically place a tube directly into the patient's stomach, or to let the patient die.

Ideally, the AD patient will have addressed this situation in his or her advance directives. Yet, even if he or she did this, core ethical questions still remain: When the psychiatrist and the patient were discussing advance directives, could the patient accurately imagine how it would feel to no longer recognize

anyone and to be fed in an artificial way? If he or she, or his or her family members for that matter, was not able to imagine this at all, should this matter ethically?

Repeated nasogastric tube insertions are, for example, reported by competent patients to be very unpleasant. Patients with AD may not understand what is being done. They may try to pull their tubes out and potentially have the additional discomfort of being held in restraints. Post suggests, accordingly, that if this point is reached, the doctor should carefully consider

whether it makes sense to go ahead and provide artificial feeding by either approach, knowing that over the subsequent days the patient's

burdens relative to his or her benefits most likely will become worse.⁶ This is especially the case if the patient loses the ability to swallow, thus risking aspiration. Post states, "Although ANH [artificial nutrition and hydration] might protract dying for several weeks or even several months, death," he says, "remains imminent...Rather than apply ANH, hospice care is the humane alternative."⁶

Post's insights are invaluable. Yet, there is a risk on the other extreme that psychiatrists could over apply them. Despite the similarities among patients with AD, each patient's response, even to the same external circumstances, is unique.²⁸⁻³⁰ Thus, if some patients could speak, they might want to stay alive even under the most dire medical circumstances.

One factor, perhaps the most likely, to affect this decision is the love and quality of care the AD patient continues to receive from significant others. Caregivers can, for example, talk to the patient soothingly while they are feeding, dressing, bathing, or moving him or

her. This kind of loving behavior can greatly reduce stress in the AD patient by personalizing the interaction and possibly providing some positive experiences, even when caregivers are administering tube feedings.^{31,44}

Caregivers may even be able to reverse the patient's situation after he or she has lost the capacity to eat. One such person reports, "The caregiver may place his or her hand over the patient's hand, place a small amount of sweetened food, such as applesauce, on the tip of a large spoon, move it to the patient's mouth, and place the tip between the patient's lips to stimulate eating."⁴⁴

It may be that psychiatrists can pursue an intermediate approach between keeping the AD patient alive and withholding life-preserving measures once artificial feeding becomes necessary. Since there are now more reliable measures for determining when incompetent patients are experiencing substantial pain, this decision may be based on the extent to which the pain is both constant and severe. If the patient seems, overall, to be experiencing more pleasure than pain, it may be justifiable to provide continuing life-sustaining measures even if he or she has reached a point where he or she can no longer eat enough to sustain body weight. If, at some later time, the patient takes a turn for the worse, this benefit/burden ratio can be reassessed. It may be that the life-sustaining measures may then need to be withdrawn. What may prevent doctors from doing this is that often the caregivers find it exceedingly difficult to stop providing food and water once tube feedings have begun or a stomach tube has been surgically inserted. Psychiatrists can help in these situations. Post implicitly suggests, "The clinician

should proactively clarify for caregivers the burdens of invasive treatments to spare them the sense of guilt associated with not doing everything to prolong life."⁴⁶

CONCLUSION

This article has discussed only a subset of the many ethical questions that arise when treating AD patients.⁶ The dilemmas of truth telling versus lying and allowing some patients to more easily die are open to debate, but since some suggestions I have made are counter-intuitive and, thus, not self-evident, I have included these particular ethical dilemmas in this article.

There are several ethical questions I have not included in this article. One such question is: When should psychiatrists treat AD patients with atypical antipsychotic drugs? While there is general consensus that these drugs should have a place in treatment if the patient's quality of life becomes greatly impaired,^{45,46} there is debate on at what point their usage should occur.⁴⁷

Another question not covered in this article is: When, if ever, should AD patients be permitted to

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participate in research. In this case, this consensus is that these patients should be able to participate in AD research.⁴⁸ If not, this would violate the principles of both justice and providing these future patients benefit. The question that remains here is at what point the risks become so great that these principles should be offset.⁴⁹

The reason I did not provide discussions on the use of antipsychotics or participation in research in this article is because by and large, no radical challenges to traditional ethical paradigms are at stake when dealing with these matters. Further, how psychiatrists should resolve these questions is more self-evident and consistent with common, prudent, clinical sense.

Another principal ethical controversy I did not address in this article that doesn't meet the criteria just described is the following: What standard should surrogate decision makers use when making decisions for severely impaired AD patients. More specifically, should decisions for these patients be based on who they once were or on who they have become? Here there are two views that remain diametrically opposed. Some feel that decisions should be based on who the patient used to be to minimally respect patient autonomy. Others say that doing this unduly disrespects the wholly different person the patient may have become. A third view is that these two identities aren't in significant ways irreconcilable: "But what each fails to realize is that our

responsibility as surrogate decision makers is to put that self back together."⁵⁰ While this last controversy doesn't allow an easy conclusion, hopefully the issues that have been addressed in this article, in contrast, give rise to practical, present applications.

In summary, the practicing psychiatrist should be able to apply the following:

1. During the initial stages, psychiatrists should keep in mind that it is important for these patients to remain in control and as fully involved as possible with their families. Accordingly,

particularly at this time, psychiatrist should give ethical priority to furthering the patient's interests by informing him or her honestly about AD, help the patient get further testing if desired by the patient, and discuss advance directives with the patient in the presence of his or her family. Initially, the psychiatrist should fully involve AD patients in all decisions regarding their care.

2. As a patient's cognitive capacities and behavioral control worsen, this same degree of honesty may or may not still be ethically best. At this time, the psychiatrist may want to give greater consideration to condoning if not advising AD patients' family members to do what gives them the least amount of stress, which in turn will prevent undue stress on the patient. The overriding ethical guideline here may be for caregivers to try to meet the patient's emotional needs more as the disease progresses. This may mean that caregivers will engage in lying to the patient. What caregivers should do in these instances is presently, however, clinically and ethically controversial. Some patients may do better if their caregivers remain wholly honest despite the emotional stress. Psychiatrists may justifiably alter their advice based on what they believe is best for each patient, which in turn depends on how each patient's family members feel.⁵¹ As an AD patient's condition worsens, the psychiatrist should support caregivers who feel they must lie to emotionally protect the patient.

3. During the last stage of AD, when the patient is on a downhill course and will most likely die in the foreseeable future, psychiatrists

should regularly assess each patient's ongoing relative benefits and burdens. When the AD patient shows signs that he or she can't eat enough without artificial nutrition to maintain weight, the psychiatrist should consider the possibility with the family that it may be time to allow the patients to die. The psychiatrist and family

members should consider this more strongly if at a later time the patient can no longer eat at all. Psychiatrists should also consider that, even in the final stages of AD, the patient still may have adequate reasons to want to live and if he or she could speak, might express this. Chief among the factors that may make a patient want to live are lack of severe pain and continuing intimate interactions with loved ones. The psychiatrist should be open to both allowing the AD patient to die and to initiating life preserving methods if the AD patient can still find life in some way to be meaningful. Having periods of time that are free from intense pain and having loved ones present are, for instance, cardinal examples.

Today when dealing with severely debilitating diseases, psychiatrists are no longer able or expected by patients and their families to provide all or most of the care that patients need. This is particularly true when patients have AD. The main task of the psychiatrist ethically is to use his or her moral training, intuition, and reasoning not to make decisions for

the patient him- or herself but to assist the AD patient and family members in making their own decisions. When these patients are first ill, psychiatrists should accordingly use these assets to maximize the patient's capacity to continue to be fully autonomous. In the middle and last phases, they should use these assets to help the families better cope with the situation and provide the patient positive support.

The bases of the suggestions I have made in this paper are not products of applying moral principles based on thought or on my clinical experiences, though these indeed have confirmed the importance of what I have said. Rather, my suggestions are based on new thinking influenced by patients and their families. I refer all readers to the following particular seminal writings: Mittelman, et al.,⁵ Coste,²⁸ Kuhn,²⁹ and Bravo, et al.³¹

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